'I thought it would go away': patient denial in breast cancer

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Summary

A significant proportion of patients with cancer present late to the doctor. The characteristics of these patients and the reasons behind their delaying behaviour is poorly understood. In this study a group of 30 women with breast cancer who delayed their presentation were compared with a randomly selected group with the same disease. The women who presented late did not appear to fit into any particular socio-demographic category, but examination of their histories revealed widespread denial of illness and a diversity of beliefs and behaviour.

Introduction

The reasons why some patients with physical illness present late to the doctor are poorly understood. Fundamental to such behaviour is the concept of denial[1]. This may be described as 'conscious' or 'unconscious' although these are difficult to distinguish, and indeed the two are often inter-related, and seen together in one individual. It is commonly assumed that late presentation of illness is a direct and damaging consequence of denial. Here, the denial can be viewed as a maladaptive behaviour, rather than a healthy and protective defence mechanism. This view is illustrated by a recent proposal that denial of physical illness should be classified as a sub-type of psychiatric disorder in DSM-IV (The Diagnostic and Statistical Manual of the American Psychiatric Association)[2].

Little is known about the factors which contribute to delay in presentation of cancer. A previous US study of 563 patients showed that 15.6% delayed their presentation by a year or more[3]. This was related to lower social class and avoiding the word 'cancer'. A British study specifically looking at cancer of the breast, found that 22 (33%) of 67 patients delayed seeking treatment for more than 3 months, with four delaying for a year[4]. This study showed an association between delay and habitual denial in the face of life crises, but not with ignorance of the diagnosis.

We decided to study a group of women with breast cancer who delayed their presentation to medical services to an extreme degree to see whether this was associated with psychiatric disturbances and socio-demographic variables, and to gather clues as to why such behaviour occurs.

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Table 1. Characteristics of delayers and controls with breast cancer

	Delayers (n=30)	*Controls (n=30)*	
Mean length of history (months):	17.4	2.5	$P<0.0001$
Size of tumour (cm^2)	54.7	27	$P<0.05$
Age (years)	62.5	63.0	NS
Marital status*			
Married	14	17	
Single	10	4	Chi square
Widowed	6	8	$P=0.2$
			*data missing from one control
Reason given for referral			
Routine	2	2	
Screening	0	1	
Pain	2	1	
Bleeding	5	0	
Lump	11	14	
Other	7	6	

Methods

Out of 693 women with breast cancer who were referred to a Department of Radiotherapy and Oncology, over a 3 year period (August 1987 to August 1990) 30 (7.2%) were noted by the responsible clinician to have significantly delayed their presentation. Details were obtained from medical notes and compared with those of 30 other women with breast cancer randomly selected from the clinic.

Results

The results (Table 1) show that delayed presentation is confirmed by longer histories (mean=17.4 months) - often underestimated by patients - and associated with larger tumours. There was no significant age difference between the two groups. Examination of marital status showed that 10 of the cases were unmarried compared to four of the controls, suggesting that life-long lack of intimacy may inhibit presentation of breast disease, but this difference was not statistically significant. Two cases and no controls had a past psychiatric history, depression in both instances, recorded in the case notes. No differences in ethnicity or occupation were detected (see Table 2).

Reasons for referral other than those listed included two cases of cord compression amongst the delayers and being persuaded by a relative or GP. Offensive smell was never given as a reason for attendance but

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Table 2. Selected case descriptions on 10 patients with delayed presentation

Case	Age (years)	Length of history (months)	Size of tumour	History
AH	70	12	11×10 cm²	Presented with fungating lesion with running and staining of clothes. 'I thought I'd have to have the breast off and there was no one to talk to because I live on my own'. Finally told niece who told her to go to GP.
WK	58	1++	8×10 cm²	Married 43 years to lorry driver. No children. Emergency treatment for cord compression. 'Never noticed lump, it wasn't painful'. Said husband never noticed or 'didn't mention it'. Has strong army background 'Our family's never been ill'. Stoical: 'No point dwelling on what might have been'.
ML	47	16	9×9 cm²	Single, Roman Catholic hotelier. 'I thought it would go away.' Described as 'remarkably well' and 'symptomless'.
RC	69	72	12×10 cm²	Single woman living alone. Presented at A&E with profuse bleeding from offensive, fungating tumour. Long history of depression treated as outpatient. Responded to imipramine.
PS	62	6+	?	Guyanan, Hindu woman. Formerly sales manager for a large department store. Son-in-law consultant physician. Described self as 'sinful and disfigured' due to cancer. Hid herself away from family.
NP	78	4+	10×6 cm²	Single woman who lived with disabled elderly sister. She insisted on staying at home to look after her until no longer able. Became 'tearful & fearful' when told diagnosis.
RN	52	9	?	Married housewife. Presented due to odour. Previous history of hydatidiform mole. Many family problems. Son took overdose day before she went to GP. Daughter is a nurse.
AW	45	36	4×5 cm²	Single parent with one daughter (in care). Did not present because 'lump wasn't painful'. Emergency admission with paraplegia and incontinence due to spinal metastases. Father died 10 years previously. Could not accept this or go to funeral.
CS	58	9	3×4 cm²	Single teacher, presented with shortness of breath (pleural effusions). Past history of hysterectomy and 'nervous breakdown' in 30s treated as OP. Grandmother and aunt both died of Ca breast.
MN	72	48	4×4 cm²	Married. Presented to GP with discharge from fungating tumour. Much persuasion to attend hospital. Defaulted after single course of DXT. Wrote letter cancelling appointment saying 'I am reasonably well at present'.

was frequently noticed by relatives and doctors of patients presenting late.

Overall, left-sided tumours were more common compared to right-sided (35 vs 25), as has been noticed previously[5], but no difference in laterality was detected between the delayers and the controls, going against 'neurological denial' which invariably involves the left side of the body[6].

Discussion

Our results show that extremely late presentation, resulting in massive fungating lesions, is still seen in patients with breast cancer despite increased public awareness of the need for early detection. The study was based on retrospective review of case records rather than interviews which limits the contextual detail available. Nevertheless it emerges that patients who present late do not appear to fit into any particular demographic category. They are neither ill-educated nor psychotic. None of the patients claimed to be unaware of the seriousness of their condition when asked directly by the doctor. The case reports illustrate the diversity of beliefs and behaviour amongst delayers. Fear of both illness and mastectomy are prominent; social pressures and responsibility, past psychiatric history, modesty and cultural beliefs all appear to be important with denial in a variety of guises being a common denominator.

Increasing awareness of the seriousness of a breast lump may not improve compliance in this group but rather, strategies aimed at aiding the patient's mastery over illness. This may be a more successful means of overcoming pathological denial[7]. It is possible that similar psychological mechanisms underlie both denial of illness and reluctance to participate in screening programmes[8,9]. If this is indeed the case, it may have implications for how the benefits of screening should be conveyed. However from our study, it appears that the denial of each patient needs to be understood individually, and in this way the doctor may gain the patient's trust and encourage acceptance of treatment.

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